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Family Health Dataline

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- Of 198 infant deaths reviewed which occurred during 1992-95:
- 100% of infants who died of sudden infant death syndrome (SIDS) and for whom this information was known were found in the prone sleep position, had been placed to sleep on inappropriate bedding, or had a mother who smoked cigarettes.
- 10 infants who died of a congenital disease had a potentially non-lethal anomaly, including four who had a condition which went unrecognized or untreated by a rural health care provider.
- Abuse or neglect contributed to 15 infant deaths, primarily among the non-Alaska Native population of Anchorage; five of these infants had been previously reported to the Alaska Division of Family and Youth Services.
- Infectious diseases caused or contributed to the deaths of 28% of infants.
- 10 infants died due to injuries, primarily suffocation.

1996 Alaska Maternal-Infant Mortality Review Results

In this issue of the Dataline, we present results of the Alaska Maternal-Infant Mortality Review (MIMR) for 1996. This review focuses only on infant deaths and includes those deaths which were reviewed during 1996 as well as deaths reviewed during previous years. Previous issues of the Dataline present in detail the MIMR process (Alaska Division of Public Health, 1996). Briefly, staff with the Alaska Division of Public Health, Section of Maternal Child and Family Health identify infants who have died and collect information from maternal and infant medical records, autopsy reports, first-responder (e.g., state troopers, paramedics, etc.) reports, and home interviews. Members of the infant mortality review team then meet to review each case, establish a committee or consensus cause of death, and identify potentially preventable risk factors.

Cause of Death Findings

The MIMR committee reviewed 198 infant deaths which occurred during 1992-95 including 60 which occurred during 1992, 66 which occurred during 1993, 55 which occurred during 1994, and 17 which occurred during 1995. Of the 272 total deaths which occurred during 1992-94, the committee reviewed 67%.

Of the deaths which were reviewed, the committee identified sudden infant death syndrome (SIDS) as the most common underlying cause of death (27%) followed by premature birth (22%), congenital anomalies (21%), infectious diseases (9%), injury (5%), other (5%), and unknown (11%). Agreement between the death certificate and committee cause of death ranged from 75-88% and did not vary significantly by year or whether an autopsy was performed (Table 1). Using the consensus cause of death as the gold standard, the sensitivity and positive predictive value of the death certificate cause of death varied considerably by the reported cause (Table 2).

Table 1. Agreement between the consensus and death certificate cause of death, by year; Alaska MIMR, 1992-95

Agreement	1992		1993		1994		1995	
	Total	Autopsied	Total	Autopsied	Total	Autopsied	Total	Autopsied
Yes	53	24	51	24	44	29	15	6
No	7	6	15	8	11	9	2	1
Percent agreement	88	80	77	75	80	76	88	86

Table 2. Sensitivity and positive predictive value of the death certificate cause of death*; Alaska MIMR, 1992-95

	SIDS	Prematurity	Congenital	Infection	Injury	Other	Unknown
Positive predictive value	81	93	88	71	100	50	78
Sensitivity	100	98	100	67	70	100	33

*Consensus cause of death was used as the gold standard

Recommendations

Similar to results from last year, our data show a considerable disagreement between the death certificate and consensus cause of death. This agreement was no better when an autopsy was performed. This may suggest that current autopsies do not add to the accuracy of death certificate causes of death. It is perhaps more probable, however, that assignment of the cause of death presents greater difficulties for out-of-hospital deaths which constitute the majority of deaths receiving an autopsy. Additionally, we found that the consensus cause of death disagreed with the cause of death reported by both health care providers (i.e., deaths which did not receive an autopsy) and pathologists. This suggests that all persons filling out death certificates must take care to report accurately the underlying and immediate causes of death.

Several specific issues may allow more accurate determination of the cause of infant deaths. For all out-of-hospital deaths, a death scene investigation should occur.

In the absence of trained medical investigators, first responders should receive training in conducting a death scene investigation. For deaths which receive an autopsy, particularly out-of-hospital deaths and suspected cases of SIDS, a standardized autopsy form should be used and a minimum set of data collected.

- Persons filling out death certificates should identify accurately the immediate and underlying causes of death.
- A death scene investigation should occur for all out-of-hospital infant deaths conducted by a trained investigator.
- The medical examiner's office should have adequate resources to conduct appropriate investigations of infant deaths.
- Where data are lacking or inconclusive, persons filling out death certificates should use other appropriate terminology such as "asphyxia of unknown etiology" or "sudden unexplained infant death."

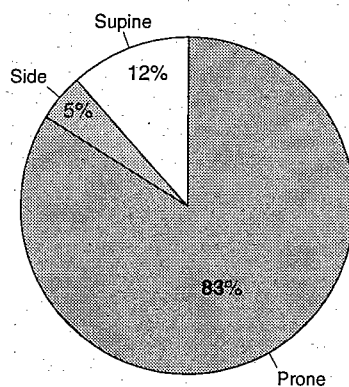
ology" or "sudden unexplained infant death."

Sudden Infant Death Syndrome Findings

The committee identified 54 deaths as due to SIDS. The age at death ranged from 19 to 255 days (median, 101); two deaths occurred at less than 1 month and seven deaths occurred at greater than 6 months. Of the 54 deaths attributed to SIDS, sleep position was known for 43. Of these 43 infants, 36 (84%) were put to sleep in the prone position 2 (5%) on their side, and 5 (12%) in the supine position (Figure 1). Bedding was known for 46 infants. Of these 46, 23 (50%) died in a crib or bassinet, 16 (35%) on an adult mattress, 2 (4%) on a couch, 1 (2%) on a water bed, and 4 (9%) on another surface.

Compared to infant deaths where the mother did not smoke before pregnancy, infant deaths where the mother smoked were more likely to be due to SIDS than other causes (risk ratio [RR], 1.7; 95% confidence interval [CI], 1.1

Figure 1. Sleep position for infants who died of sudden infant death syndrome; Alaska MIMR, 1992-95



to 2.7) as was true for maternal smoking during pregnancy (RR, 2.0; 95% CI, 1.3 to 3.1).

Of the 54 infants who died of SIDS, 49 had one or more of the following risk factors: prone sleep position, sleeping outside of a bassinet or crib, maternal smoking, or a heavy blanket placed over them. Of the remaining 5, none of the mothers smoked before or during pregnancy; information on prone sleep position and bedding was only known for one infant each. Among infants who died of SIDS and who had information available for all the mentioned risk factors, all were positive for one or more risk factors.

Recommendations

The data presented above emphasize the main risk factors for SIDS: prone sleep position, inappropriate bedding, and maternal smoking. Numerous studies have demonstrated an association between prone sleep position and SIDS (Willinger et al, 1994), an association supported by our data. A national Back to Sleep Campaign has focused on educating mothers that, in the ab-

sence of medical contraindications, they should place their infants to sleep on their backs. Recent national data suggest that while most health care providers and lay public are aware of the recommendations for supine sleeping, some demographic groups remain unaware of this recommendation (National Institute of Child Health and Human Development, unpublished data). This underscores the need for culturally appropriate, sustained education campaigns to decrease the risk of SIDS among all risk groups.

We do not know the underlying prevalence of infants who sleep outside of cribs or bassinets. It seems likely that most infants who sleep with their parents do not suffer adverse consequences. Because soft bedding may impair an infant's ability to maintain adequate respiration, infants should not be placed to sleep on couches, pillows, bean bag chairs, or other soft surfaces.

- A sustained, culturally appropriate educational campaign in Alaska should promote awareness of risk

factors for SIDS.

- This campaign should recommend supine sleep position, cessation of cigarette smoking by pregnant women and mothers of newborns, and use of appropriate bedding.
- This campaign should occur through various outlets including different media sources, health care providers, and centers of public gathering.
- A survey of target audiences, including parents, grandparents, and persons of different racial and ethnic groups, should occur to determine the success of the Back to Sleep Campaign in Alaska.

Prematurity Findings

The committee identified 43 deaths due to premature birth. The gestational age of these infants ranged from 21 to 30 weeks with a mean of 3.6 weeks; 35 (81%) had a gestational age of less than 26 weeks. The age at death of these infants ranged from several minutes to 46 days; 29 infants (67%) died during the first 24 hours of life and 38 (88%) during the first 7 days (Figure 2).

Compared to mothers of infants who died of another cause, mothers whose infants died of prematurity had a higher risk of having had a previous preterm infant, although not a previous elective abortion or miscarriage (Table 3).

Although the committee identified prematurity as the primary cause of death for 43 infants, for many of these infants infectious diseases contributed to death. Nine infants had a positive culture with a known fetal or neonatal pathogen (including seven with a positive culture collected within 24 hours of birth), 15 had negative cultures, and 19 had no cultures obtained. All 19 infants who did not have a culture obtained died within 24 hours of birth.

Of the 34 infants who did not have a positive culture, 18 infants had evidence of an infectious contribution to death. This includes three who had pathologic evidence of chorioamnionitis and whose mothers had a positive culture with a known fetal or neonatal pathogen at the time of birth and 15 who had pathologic evidence of chorioamnionitis.

Recommendations

Our results confirm that to decrease mortality from premature births, we must discover ways to prevent women from delivering prematurely rather than hope to improve treatment once birth has occurred. Over 81% of infants were born at less than 26 weeks and most of these died within the first few hours of life. We found that a previous preterm birth placed women at risk of having an infant die of prematurity. Additionally, many infants who died of prematurity had evidence that an infectious etiology contributed to their preterm birth. These results agree with previous studies (Andrews et al, 1995; de Araujo et al, 1994) which suggest that

Figure 2. Age at death for infants who died due to premature birth; Alaska MIMR, 1992-95

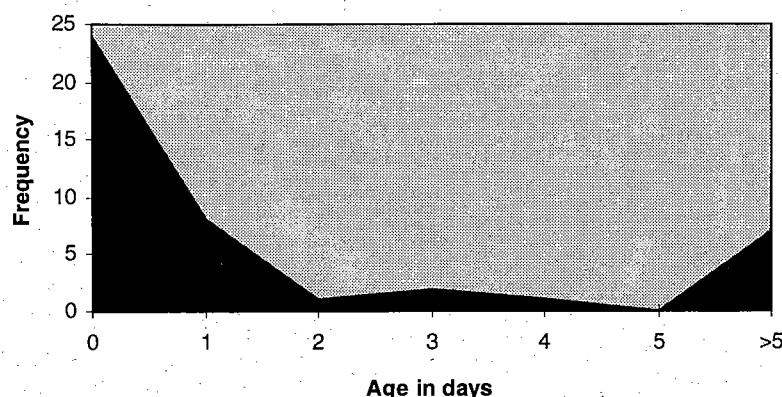


Table 3. Maternal risk factors for infant death due to prematurity compared to other infant deaths; Alaska MIMR, 1992-95

Maternal risk factor	Yes (% with death due to premature delivery)	No (% with death due to premature delivery)	Odds ratio (95% CI)
Previous premature delivery	13 (33)	19 (14)	3.0 (1.2, 7.3)
Previous miscarriage	12 (30)	33 (22)	1.5 (0.6, 1.4)
Previous elective abortion	10 (25)	40 (27)	0.9 (0.4, 2.1)
Adequate prenatal care	32 (74)	81 (52)	2.7 (1.2, 6.3)

recurrent or chronic gynecologic infections in women may predispose them to recurrent preterm deliveries. Interestingly, health care providers had obtained cultures on all infants who survived at least 24 hours but only for 10 of 29 infants who died at less than 24 hours of age.

In addition to contributing to preterm birth, infectious diseases may also contribute substantially to mortality once a premature infant is born: nine infants had at least one positive culture with a suspected pathogen before death, representing 38% of all infants who had a culture obtained.

- Efforts to decrease mortality due to preterm birth should emphasize prenatal rather than postnatal factors.

- Emphasis should be placed on ascertaining potential infectious causes of preterm birth through culture and pathologic examination of placental tissue, cervical cultures, and amniotic fluid cultures where appropriate.

- Efforts to prolong survival of prematurely born infants should emphasize respiratory status and infectious diseases.

Congenital Anomalies

Findings

The committee identified 42 deaths as due to congenital anomalies. Of these 42 infants, 32 had lethal congenital anomalies including 16 with chromo-

somal monosomies or trisomies, three with neural tube defects and no evidence of chromosomal monosomy or trisomy, six with congenital heart defects and no evidence of a chromosomal anomaly or neural tube defect, and seven with a variety of other defects.

Of the 10 infants with potentially treatable conditions, four had a congenital heart defect including three who died after a rural physician either failed to diagnose a condition, delayed diagnosis, or delayed treatment. Three infants died during or immediately after surgery including two with unrecognized sepsis or pneumonia. One infant received care of questionable quality from a village health aide. One infant had a post-surgical complication that went unrecognized by the mother. Finally, one infant may have had a lethal lesion but also had sepsis and pneumonia

In Alaska, the majority of infants whose cause of death was attributed to congenital anomalies had a lesion which was not amenable to treatment. To have a large impact on congenital disease mortality, investigators must identify preventable factors such as folic acid supplementation for pregnant women to prevent neural tube defects. To contribute to the understanding of birth defects in Alaska, the Alaska Division of Public Health, Section of Maternal, Child, and Family Health has initiated the Alaska Birth Defects Registry.

Of infants who died with a potentially treatable lesion, three

died because of a physician failure to diagnose or treat the condition appropriately. Delivery of medical care in remote areas has many challenges and keeping pace with technological advances ranks high among them. Public health officials and specialists should encourage wide dissemination of knowledge through such avenues as the Internet, telemedicine, and newsletters. Additionally, rural practitioners have a responsibility to access these sources of information. Similar to deaths due to prematurity, infectious causes may have contributed to the deaths of several infants with potentially treatable congenital anomalies.

- Public health officials and specialists should encourage wide dissemination of new advances in medical knowledge through such avenues as the Internet, telemedicine, and newsletters.
- Rural practitioners must have the means and desire to access these sources of information.
- Surgeons and other health care practitioners should be suspicious of infectious causes of clinical deterioration in infants with congenital anomalies.

Injuries

Findings

The committee identified 10 deaths as due to injuries. Of these deaths, six were probably due to suffocation, including five re-

lated to inappropriate bedding and one due to a foreign body aspiration. Two deaths occurred after a motor vehicle crash including one where an infant was not in a car seat, one occurred by drowning, and one resulted from carbon monoxide poisoning.

Recommendations

The majority of infant deaths were related to suffocation associated with inappropriate bedding. However, all of these infants died of potentially preventable causes.

- Health care providers should stress to the mothers of newborns the importance of appropriate bedding for infants, the importance of using car seats, and the danger of leaving infants unattended near bodies of water or leaving inappropriate objects within reach of infants.
- All parents should have access to car seats regardless of their financial status.

Unknown Cause of Death

Findings

The committee identified 21 deaths where the cause of death could not be determined. Of these, 10 were possibly due to SIDS, seven to infection, seven to abuse or neglect, two to overlie, and two to congenital anomalies. Of the 21 infants, 16 died outside of the hospital.

Recommendations

These data emphasize the importance of conducting thorough investigations of out-of-hospital deaths through the use of complete autopsies, death scene investigations, and appropriate review of clinical data. For example, a thorough investigation may help to separate deaths due to SIDS from those due to infectious causes, abuse or neglect, or accidental suffocation. Prevention efforts vary widely for these different causes as do the response to the infant's death. For example, a death due to SIDS will lead to the initiation of grief services, while a death due to abuse or neglect may lead to the involvement of the criminal justice system. Interestingly, two infants may have died due to overlie. As discussed in the SIDS section above, it is likely that most parents can sleep with their children without adverse effects. An exception to this principle may exist when the parent has an altered mental status, particularly due to the ingestion of alcohol or other substances.

- All out-of-hospital deaths should have a thorough investigation through the use of complete autopsies, death scene investigations,

and appropriate review of clinical data.

- Parents who have an altered mental status should not sleep with their infants.

Abuse or Neglect

Findings

Of the 10 infants who died from an injury, the committee suspected that four died from intentional injuries. Additionally, of the 21 infants whose cause of death could not be determined, for seven the committee felt that abuse or neglect contributed to or led directly to death. A further four infants died of other causes but had severe failure to thrive in the absence of known organic etiologies. Overall 15 of the 198 deaths reviewed (8%) may have resulted from or been contributed to by abuse or neglect.

Compared to deaths caused by SIDS, risk factors for death contributed to by abuse or neglect included having had a referral to the Division of Family and Youth Services (DFYS), non-Alaska Native race (among suspected abuse or neglect deaths, 11 occurred among whites, three among blacks, and one among Alaska Natives), uninsured or on

Medicaid, Anchorage residence, and unmarried parents. A previous elective abortion was protective (Table 4). Only referral to DFYS was significant at the 95% confidence level.

Recommendations

Our data suggest that approximately 8% of infant deaths are caused or contributed to by abuse or neglect. Despite this, few instances of prosecution have occurred. While the committee did not know why this was the case, it may be that insufficient information was gathered to warrant further investigation or that available information was not critically reviewed prior to assigning an unintentional intent to the case. Five of the infants had been reported to DFYS, yet still died of suspected abuse or neglect suggesting a failure in the system designed to protect children. Ten children were never reported to DFYS suggesting a failure of health care providers and other members of communities to identify and report children at risk.

Most of the deaths related to suspected abuse or neglect occurred in Anchorage among non-Alaska Native races suggesting specific groups who might be targeted for

Table 4. For various risk factors, the risk ratio for dying from suspected abuse or neglect compared with SIDS; Alaska MIMR, 1992-95

Risk factor*	Yes (% suspected abuse/neglect)	No (% suspected abuse/neglect)	Risk ratio (95% CI)
Referral to DFYS	5 (100)	10 (17)	6.0 (3.4, 10.6)
Mother non-Alaska Native	14 (9)	1 (2)	3.9 (0.5, 28.7)
Uninsured or on Medicaid	7 (29)	3 (9)	3.1 (0.9, 10.8)
Anchorage resident	10 (33)	5 (13)	2.5 (1.0, 6.6)
Unmarried	11 (28)	4 (15)	1.9 (0.7, 5.2)
Previous elective abortion	1 (6)	17 (26)	0.2 (0.0, 1.5)

* Overall, 15 infants died with suspected abuse or neglect and 52 died with SIDS; however, risk factor information was not known for all deaths.

intervention. Interestingly, a previous elective abortion appeared to be protective (although not at a statistically significant level). While the reason for this finding is unknown, women who have limited access to abortion services, either through cultural, financial, or geographic barriers, may be more likely to have unwanted children. These children might then be at higher risk for abuse or neglect.

- All out-of-hospital deaths should have a thorough investigation through the use of complete autopsies, death scene investigations, and appropriate review of clinical data.
- Where a suspicion that abuse or neglect contributed to an infant death exists, further investigation should be considered.
- DFYS should review files for the five infants identified in their database to determine if specific errors occurred which allowed these infants to die of suspected abuse or neglect despite previous reporting to DFYS.
- Health care providers should report all suspected cases of child abuse and neglect to DFYS and DFYS should be provided with adequate resources to investigate these reports.
- Specific preventative and investigative interventions should be directed toward the non-Alaska Native population of Anchorage.

Infectious Diseases Findings

The committee identified 18 deaths due to infectious causes. Eight cases of bronchopneumonia were identified, with death occurring outside the neonatal period for all infants; no organisms were identified for any of these cases. Seven cases of neonatal sepsis or pneumonia were identified including three due to Group B *Streptococcus*, and one each due to herpes simplex virus, *Escherichia coli*, and *Candida albicans*; for one infant, no organism was isolated but the clinical course was consistent with sepsis. Among the remaining three infants who died of an infectious etiology, one had sepsis due to *Neisseria meningitidis* and two had interstitial pneumonitis without a further etiology identified.

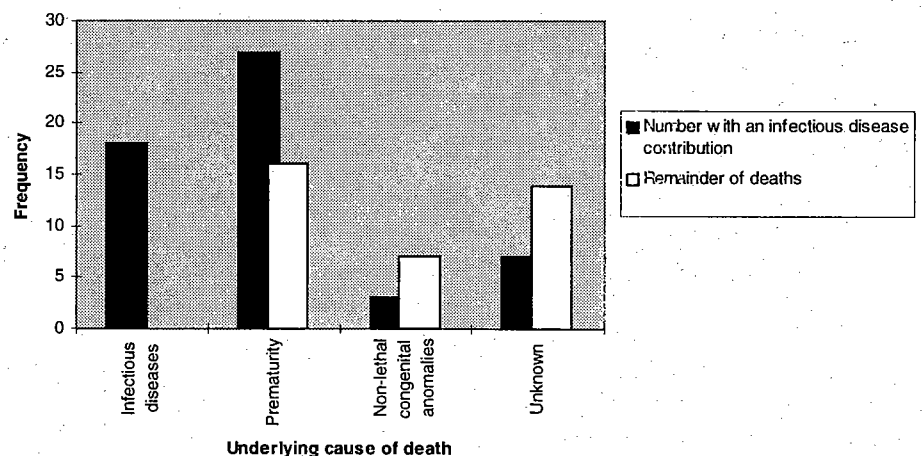
In addition to deaths due to infectious diseases, the sections on other causes of death identified many infants who had an infectious contribution to death. Three infants with a potentially non-le-

thal congenital anomaly had an infectious disease contribute to death, seven infants for whom no cause of death could be determined probably died of an infection, and among infants who died of prematurity nine had at least one positive culture with a suspected pathogen and 18 others probably had an infectious contribution to their death. Overall, this suggests that approximately 55 infant deaths in Alaska (28%) had an infectious disease contribution during 1992-95 (Figure 3).

Recommendations

Infectious diseases contribute significantly to infant mortality in Alaska, contributing to approximately 28% of infant deaths in Alaska. Despite this, many infants who die, particularly those who die out of the hospital, do not have cultures collected to determine potential infectious etiologies. From a prevention aspect, a critical difference exists between pneumonia due to *Streptococcus pneumoniae* or *Staphylococcus aureus* and one due to

Figure 3. The contribution of infectious diseases to infant mortality, by underlying cause of death; Alaska, 1992-95



Bordetella pertussis or *Hemophilus influenzae*. Infections due to the latter organisms suggest a failure in the immunization of children while infections due to the former organisms suggest a need to develop new prevention strategies.

- Infectious diseases should be considered a primary cause of infant mortality in Alaska.

- For all infant deaths where an infectious etiology is suspected, appropriate cultures should be collected, either by health care providers or at autopsy.
- Mechanisms should be developed to assure that insurance companies pay for post-mortem cultures.

Submitted by
Bradford D. Gessner, MD

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